General

Title

Sickle cell disease (SCD): percentage of children younger than 18 years of age identified as having SCD who had: (1) a pulse oximetry reading, (2) a complete blood count, and (3) a reticulocyte count performed within the same 7â€day period as part of outpatient care during the measurement year.

Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate outpatient blood testing for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium; 2014 Apr. 40 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of children younger than 18 years of age identified as having sickle cell disease (SCD) who had: (1) a pulse oximetry reading, (2) a complete blood count, and (3) a reticulocyte count performed within the same 7-day period as part of outpatient care during the measurement year. A higher proportion indicates better performance, as reflected by appropriate treatment.

This measure uses medical record data to calculate individual rates for three blood tests, as well as an overall rate that is a composite of the three individual rates:

- The percentage of children who had a pulse oximetry reading performed during the outpatient visit.
- The percentage of children who had a complete blood count performed within 7 days of the outpatient visit.

The percentage of children who had a reticulocyte count performed within 7 days of the outpatient visit.

The overall rate is the percentage of children who, during outpatient care, had a pulse oximetry reading, a complete blood count, and a reticulocyte count performed within the same 7-day period.

Rationale

Approximately 2,000 infants are born with sickle cell disease (SCD) in the United States each year, a condition that occurs predominantly in people of African and Hispanic descent. SCD is a chronic hematologic disorder, characterized by the presence of hemoglobin S. From infancy onward, the presence of this hemoglobin variant can lead to an array of serious medical conditions. Appropriate blood testing in children is crucial to establish baseline values to use as comparisons during acute illness and to detect abnormalities that presage possible illness. Clinical guidelines for SCD pediatric health maintenance recommend that blood tests should be obtained regularly throughout childhood. However, there are no existing quality measures for appropriate blood testing in children with SCD.

Evidence for Rationale

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate outpatient blood testing for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium; 2014 Apr. 40 p.

Primary Health Components

Sickle cell disease (SCD); blood testing (pulse oximetry reading, complete blood count, reticulocyte count); infants; children; adolescents

Denominator Description

The eligible population for the denominator is the number of children younger than 18 years of age with sickle cell disease (SCD) who received outpatient care during the measurement year (January 1 to December 31) (see the related "Denominator Inclusions/Exclusions" field).

Numerator Description

The eligible population for the numerator is the number of children younger than 18 years of age with sickle cell disease (SCD) who had a pulse oximetry reading, a complete blood count, and a reticulocyte count performed within the same 7â€day period as part of outpatient care during the measurement year (January 1 to December 31) (see the related "Numerator Inclusions/Exclusions" field).

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Sickle Cell Disease Prevalence and Incidence
Sickle cell disease (SCD) is one of the most common genetic disorders in the United States (U.S.) (Kavanagh et al., 2011). The National Heart, Lung and Blood Institute (NHLBI) (2002) estimates that 2,000 infants are born with SCD in the U.S. each year. SCD affects 70,000 to 100,000 children and adults in the U.S., predominantly those of African and Hispanic descent (Hassell, 2010).

Sickle Cell Disease Pathology and Severity
Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with the condition (Kavanagh et al., 2011).

Sickle Cell Disease Burden in Daily Life
The effect of SCD on children and families is significant; severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, as well as on sleep and social activities (Lemanek, Ranalli, & Lukens, 2009; Alvim et al., 2005). Although medical management of SCD continues to improve over time, 196 children in the United States died from SCD-related causes between 1999 and 2002 (Yanni et al., 2009).

Sickle Cell Disease Cost
In a study of health care utilization among low income children with SCD between 2004 and 2007, 27% of these children required inpatient hospitalization and 39% used emergency care during a year. Of these children, 63% averaged one well-child visit per year and 10% had at least one outpatient visit with a specialist (Raphael et al., 2009). Patients with SCD use many parts of the health care system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were $23,000 for children with private insurance and $18,200 for children enrolled in Medicaid (HCUPnet, Healthcare Cost and Utilization Project, 2012). Kauf et al. (2009) estimate the lifetime cost of health care per patient with SCD to be approximately $460,000.

See the original measure documentation for additional evidence supporting the measure.

Evidence for Additional Information Supporting Need for the Measure

Alvim RC, Viana MB, Pires MA, Franklin HM, Paula MJ, Brito AC, Oliveira TF, Rezende PV. Inefficacy of piracetam in the prevention of painful crises in children and adolescents with sickle cell disease. Acta Haematol. 2005;113(4):228-33. PubMed

Hassell KL. Population estimates of sickle cell disease in the U.S. Am J Prev Med. 2010 Apr;38(4 Suppl):S512-21. PubMed

HCUPnet. Healthcare Cost and Utilization Project. [Web site]. Rockville (MD): Agency for Healthcare Research and Quality; 2006-2009

Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG. The cost of health care for children and adults with sickle cell disease. Am J Hematol. 2009 Jun;84(6):323-7. PubMed

Kavanagh PL, Sprinz PG, Vinci SR, Bauchner H, Wang CJ. Management of children with sickle cell

disease: a comprehensive review of the literature. Pediatrics. 2011 Dec;128(6):e1552-74.

Lemanek KL, Ranalli M, Lukens C. A randomized controlled trial of massage therapy in children with sickle cell disease. J Pediatr Psychol. 2009 Nov-Dec;34(10):1091-6.

National Heart, Lung and Blood Institute (NHLBI). The management of sickle cell disease. 4th ed. Bethesda (MD): National Institutes of Health, National Heart, Lung and Blood Institute, Division of Blood Diseases and Resources; 2002 Jun. 188 p.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate outpatient blood testing for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium; 2014 Apr. 40 p.

Raphael JL, Dietrich CL, Whitmire D, Mahoney DH, Mueller BU, Giardino AP. Healthcare utilization and expenditures for low income children with sickle cell disease. Pediatr Blood Cancer. 2009 Feb;52(2):263-7. PubMed

Steinberg MH. Management of sickle cell disease. N Engl J Med. 1999 Apr 1;340(13):1021-30. PubMed

Yanni E, Grosse SD, Yang Q, Olney RS. Trends in pediatric sickle cell disease-related mortality in the United States, 1983-2002. J Pediatr. 2009 Apr;154(4):541-5. PubMed

Extent of Measure Testing

Reliability

Data and Methods. The testing data consisted of an audit of medical records from the three largest centers serving sickle cell disease (SCD) patients in Michigan during 2012: Children's Hospital of Michigan (CHM, Detroit), Hurley Medical Center (Hurley, Flint), and the University of Michigan Health System (UMHS, Ann Arbor). Combined, these sites treat the majority of children with SCD in Michigan. Medical records for all children with SCD meeting the measure specification criteria during the measurement year were abstracted at each site. Abstracting was conducted in two phases; during Phase 1, 435 records were abstracted among the three sites. In Phase 2, an additional 237 cases were abstracted at one site. In total, 672 unique records were reviewed for children with SCD to test this measure.

Reliability of medical record data was determined through re-abstraction of patient record data to calculate the inter-rater reliability (IRR) between abstractors. Broadly, IRR is the extent to which the abstracted information is collected in a consistent manner (Keyton et al., 2004). Low IRR may be a sign of poorly executed abstraction procedures, such as ambiguous wording in the data collection tool, inadequate abstractor training, or abstractor fatigue. For this measure, the medical record data collected by two nurse abstractors were compared.

Measuring IRR at the beginning of the abstraction is imperative to identify any misinterpretations early on. It is also important to assess IRR throughout the abstraction process to ensure that the collected data maintain high reliability standards. Therefore, the IRR was evaluated during Phase 1 at each site to address any reliability issues before beginning data abstraction at the next site.

IRR was determined by calculating both percent agreement and Kappa statistics. While abstraction was still being conducted at each site, IRR assessments were conducted for 5% of the total set of unique patient records that were abstracted during Phase 1 of data collection. Two abstractors reviewed the same medical records; findings from these abstractions were then compared, and a list of discrepancies was created.

Three separate IRR meetings were conducted, all of which included a review of multiple SCD measures that were being evaluated. Because of eligibility criteria, not all patients were eligible for all measures.

Therefore, records for IRR were not chosen completely at random; rather, records were selected to maximize the number of measures assessed for IRR at each site.

Results. For this measure, 22 of 435 unique patient records (5%) from Phase 1 of the abstraction process were assessed for IRR across the three testing sites.

Table 6 of the original measure documentation shows the percent agreement and Kappa statistic for each numerator of this measure for each site and across all sites. The agreement for each numerator is 100% and the Kappa is 1.00, indicating a perfect IRR level was achieved.

Validity
Face Validity. The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). The Q-METRIC expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans.

The Q-METRIC expert panel concluded that this measure has a high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was highly rated, receiving an average score of 8.0 (with 9 as the highest possible score).

Validity of Abstracted Data. This measure was tested using medical record data, which is considered the gold standard for clinical information; our findings indicate that these data have a high degree of face validity and reliability. This measure was tested among a total of 500 children younger than 18 years of age with SCD (Table 7 of the original measure documentation). Overall, appropriate blood testing was conducted on 89% of children with SCD (range: 52% to 97%). Pulse oximetry was conducted on 93% of children with SCD seen in outpatient clinics (range among the three hospitals was: 65% to 99%). Similarly, a complete blood count was conducted within 7 days of the outpatient visit for 90% of children (range: 55% to 98%); a reticulocyte count was conducted within 7 days of the outpatient visit for 90% of children (range: 55% to 97%).

Evidence for Extent of Measure Testing

Keyton J, King T, Mabachi N, Manning J, Leonard L, Schill D. Content analysis procedure book. Lawrence (KS): University of Kansas; 2004.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate outpatient blood testing for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium; 2014 Apr. 40 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Single Health Care Delivery or Public Health Organizations

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age less than 18 years

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Data Collection for the Measure

Case Finding Period

The measurement year

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Diagnostic Evaluation

Encounter

Patient/Individual (Consumer) Characteristic

Therapeutic Intervention

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

The eligible population for the denominator is the number of children younger than 18 years of age with sickle cell disease (SCD) who received outpatient care during the measurement year (January 1 to December 31).

Note:

> Eligible children are restricted to those with SCD variants identified in Table 1 of the original measure documentation, based on appropriate International Classification of Diseases, Ninth Revision (ICD-9) codes as documented in the medical record.
> *Intake Period*: January 1 through December 31 of the measurement year.
> *Outpatient Care*: A Health Maintenance Exam (HME) or an Evaluation and Management (E&M) visit with primary care provider or a specialist (refer to Table 3 of the original measure documentation).

Exclusions

> Inpatient stays, emergency department visits, and urgent care visits are excluded from the calculation.
> Children with a diagnosis in the sampled medical record indicating one of the SCD variants listed in Table 4 of the original measure documentation should not be included in the eligible population *unless* there is also a diagnosis for a sickle cell variant listed in Table 1.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions
The eligible population for the numerator is the number of children younger than 18 years of age with sickle cell disease (SCD) who had a pulse oximetry reading, a complete blood count, and a reticulocyte count performed within the same 7-day period as part of outpatient care during the measurement year (January 1 to December 31).

Three individual numerators and one overall composite of the three numerators are calculated:

> Pulse oximetry – The number of eligible children who had a pulse oximetry reading performed during the outpatient visit.
> Complete blood count – The number of eligible children who had a complete blood count performed within 7 days of the outpatient visit.
> Reticulocyte – The number of eligible children who had a reticulocyte count performed within 7 days of the outpatient visit.
> Overall – The number of eligible children who, during outpatient care, had a pulse oximetry, a complete blood count, and a reticulocyte count performed all within the same 7-day period.

Note:

> Evidence of a pulse oximetry reading, a complete blood count, and a reticulocyte count is determined through medical record review of outpatient visits (refer to Table 3 of the original measure documentation). Documentation in the medical record must include, at minimum, a note containing the date(s) on which a pulse oximetry, a complete blood count, and a reticulocyte count were performed. The outpatient blood tests for the management of SCD are identified in Table 2 of the original measure documentation.

Exclusions
Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Electronic health/medical record

Paper medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Measure is disaggregated into categories based on different definitions of the denominator and/or numerator

Basis for Disaggregation

This measure is disaggregated according to the following definitions of the numerator:

> Pulse oximetry – The number of eligible children who had a pulse oximetry reading performed during the outpatient visit.
> Complete blood count – The number of eligible children who had a complete blood count performed within 7 days of the outpatient visit.
> Reticulocyte – The number of eligible children who had a reticulocyte count performed within 7 days of the outpatient visit.
> Overall – The number of eligible children who, during outpatient care, had a pulse oximetry, a complete blood count, and a reticulocyte count performed all within the same 7-day period.

This measure is calculated as 3 rates as well as an overall rate that is a composite of the three individual rates.

Scoring

Composite/Scale

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Appropriate outpatient blood testing for children with sickle cell disease.

Measure Collection Name

Sickle Cell Disease Measures

Submitter

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

Developer

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

Funding Source(s)

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Composition of the Group that Developed the Measure

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Sickle Cell Disease Measure Developers:

Kevin J. Dombkowski, DrPH, MS, Research Associate Professor of Pediatrics, School of Medicine, University of Michigan
C. Jason Wang, MD, PhD, Associate Professor of Pediatrics, Stanford School of Medicine
Gary L. Freed, MD, MPH, Professor of Pediatrics, School of Medicine; Professor of Health Management and Policy, School of Public Health, University of Michigan
Samir Ballas, MD, Professor, Division of Hematology, Thomas Jefferson University
Mary E. Brown, President and Chief Executive Officer, Sickle Cell Disease Association, California
George Buchanan, MD, Pediatric Hematologist, University of Texas Southwest Medical Center at Dallas
Cathy Call, BSN, MSC, Senior Policy Analyst and Director for Health Quality Research, Altarum Institute
J. Mitchell Harris, PhD, Director Research and Statistics, Children's Hospital Association (formerly NACHRI)
Kevin Johnson, Professor and Vice Chair of Biomedical Informatics, Vanderbilt University
Peter Lane, MD, Pediatric Hematologist-Oncologist, Children's Healthcare of Atlanta Pediatric Hospital
Don Lighter, MD, MBA, FAAP, FACHE, Director, The Institute for Health Quality Research and Education
Sue Moran, BSN, MPH, Director of the Bureau of Medicaid Program Operations and Quality Assurance, Michigan Department of Community Health
Suzette Oyeku, MD, Assistant Professor of Pediatrics, Albert Einstein College
Lynnie Reid, Parent Representative
Joseph Singer, MD, Vice President Clinical Affairs, HealthCore, Inc.
Elliott Vichinsky, MD, Pediatric Hematology-Oncology, Children's Hospital and Research Center
Winfred Wang, MD, Hematologist, St. Jude Children's Hospital

Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Apr

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in January 2016.

Measure Availability

Source available from the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Web site . Support documents are also available.

For more information, contact Q-METRIC at 300 North Ingalls Street, Room 6C08, SPC 5456, Ann Arbor, MI 48109-5456; Phone: 734-232-0657; Fax: 734-764-2599.

NQMC Status

This NQMC summary was completed by ECRI Institute on January 23, 2015. This NQMC summary was verified by the measure developer on March 2, 2015.

The information was reaffirmed by the measure developer on January 7, 2016.

Copyright Statement

Production

Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: appropriate outpatient blood testing for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium; 2014 Apr. 40 p.

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